

## Patient Reported Outcome Measures

### PROMs



#### HISTORY

Quality of Life: The Assessment, Analysis and Interpretation of Patient Reported Outcome Measures. By Peter M. Fayers, David Machin 2007, 2nd Ed.

## CHECK IN

1. PROMs attempt to capture the clinician's and patient's joint expectations for the patients progress. True or False
2. PROMs measure success or failure of the Tx plan. True or False
3. One difficulty in measuring PROMs is that they are subjective. True or False
4. Subjective outcomes cannot be measured as well as objective ones. True or False

### The Elusive QoL

What are the Red Flags in Capturing Patient Impressions?

Who is asking  
Who answering  
Why are they asking

Large Degree of Subjectivity  
Is it Worth Measuring?

"observers are poor judges of patients' opinions"



### PROMs Definition

Patient-reported outcome measures (PROMs) capture a patient's perspective of the impact of care, intervention on quality of life and ability to function. These data are used to complement traditional medical outcome measures, such as the rate of complications and mortality rates, to help clinicians understand long-term patient results.

Chris Conley

### Quality of Life QoL

- It's considered a differentiator for health related quality of life (HRQL)
- Pain, nausea and vomiting underestimated considered a barrier for Tx by oncologists & pts
- Symptomatic consequences
- Most doctors report they would not tolerate them

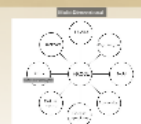
### A REVELATION

A Correlation was Found Between...  
Assessing QoL & Adherence to Tx



## THE SPEHRE OF CARE

### What is The Role Of Hospital Registries?

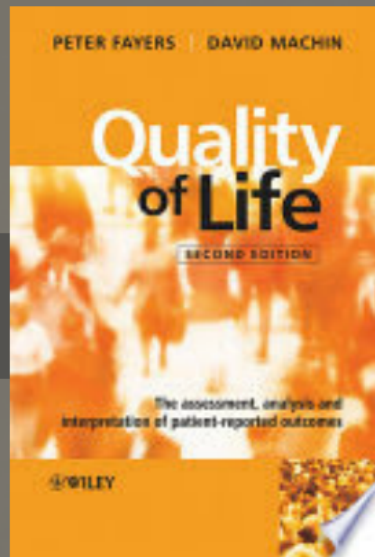


We can measure it  
We can collect it  
We can use it in our programs  
P.S. PROMs Are Evidence



# **Patient Reported Outcome Measures**

# PROMs



## HISTORY

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# Quality of Life

## QoL

- Pts consider a different bar for health related quality of life when ill
- Pain, nausea and vomiting underestimated considered a trade-off for Tx by both clinicians & pts
- Symptoms as consequences
- Most clinicians report they would not tolerate them

# The Elusive QoL

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# PROMs

## Definition

Patient-reported outcome measures (PROMs) capture the patient's perspective of the impact of care intervention on quality of life and ability to function. These statistically-valid patient-centered measures complement traditional medical outcome measures, such as surgical complications and mortality rates, to help clinicians understand long-term patient results.

Press Ganey

## THINK PATIENT-FOCUSED QUESTIONS:

- (1) "Given my personal characteristics, conditions and preferences, what should I expect to happen to me?"
- (2) "What are my options and what are the benefits and harms of those options?"
- (3) "What can I do to improve the outcomes that are most important to me?"
- 4) "How can the health care system improve my chances of achieving the outcomes I prefer?"



## All Outcomes are Commonly & Broadly Classified Into-

**CLINICAL** (e.g. cure, survival), C,CG,Pt

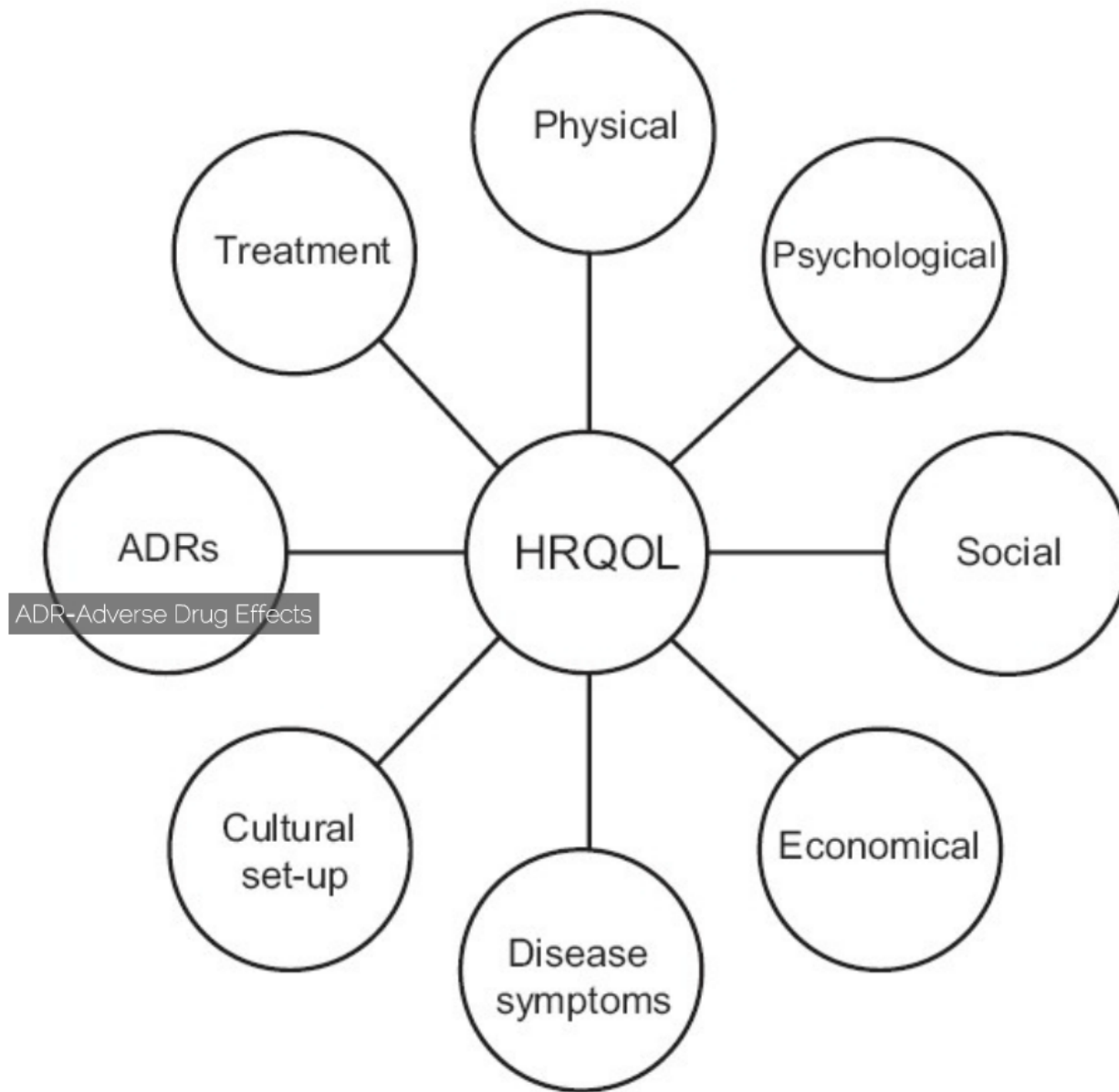
**HUMANISTIC** (e.g. role performance, emotional status) CG, Pt

**ECONOMICAL** (e.g. expenses, saving) CG, Pt

C- Clinician  
CG=Care Giver  
Pt= Patient



## Multi-Dimensional



NCCN

# Distress

NCCN NATIONAL COMPREHENSIVE CANCER NETWORK  
FOUNDATION®  
*Guiding Treatment, Changing Lives.*

gooddays

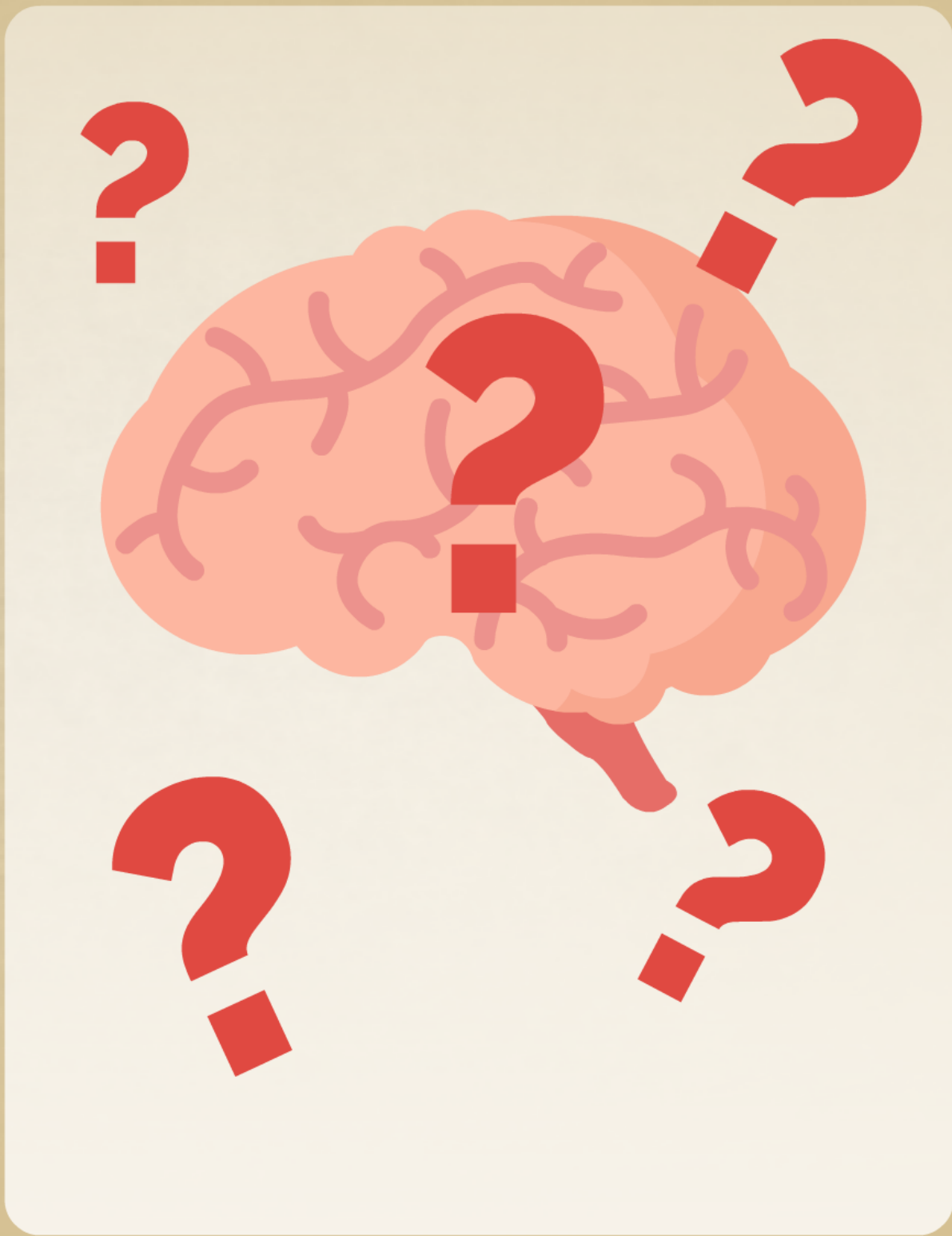
A word cloud centered around the words 'Cancer' and 'Distress'. The words are in various sizes, colors (blue, yellow, green, red), and orientations. Other words visible include: Overwhelmed, Misunderstood, Distrust, Confused, Symptoms, Helpless, Concerned, Conflicted, Death, Lonely, Panic, Side effects, Change, Loss of Faith, Coach potato, Not sleeping, Gaps in Care, Tired, Depressed, Sad, Heartbroken, Meaning of Life, Restless, Can't focus, Anxious, Fearful, Not hungry, Hopeless, Illness, Crisis, Angry, Delirium, Unmet Needs, Guilt, and Not knowing.

<https://www.nccn.org/patients/guidelines/distress/files/assets/basic-html/page-1.html>

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# What Is The Role Of Hospital Registries?







## PURPOSE OF REGISTRIES?

describing the natural history of disease, determining effectiveness, measuring or monitoring safety or harm, and measuring quality. As one reads down the list of nominated purposes of registries, the substantive role of PROs in registry design becomes increasingly clear

We can **measure it** --

We can **collect it** --

We can **use it** in our programs !

**P.S. PROMs Are Evidence**



## Patient-Centered Outcomes Research Institute

RECENT STUDIES USED DATA + PROMs TO EVALUATE

**-Surveillance**

**-Shared Decision Making**

**-Technology**

**-Compliance (for Oral Chemo)**

**-Palliative Care**

**-Communication & Perception**

# Ask The Questions

Identify The Problem/s

Are There Existing Data Sets?

Can A PROM Add Value

**WARNING: DO NOT START WITH WHO WILL DO IT**





**How To Measure**

- Develop the Measuring Tool or Instrument
- Consider Who Will Use It
- Who Will Be Measured
- For How Long & When

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[illegible]


# How Will the Results Be Used & Reported?


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To all the stuff so kindly AMRI. Thank you for ycanim service and tender treatment..  
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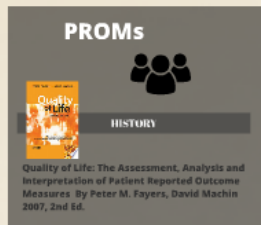
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Photo: Getty

### Quality of Life QoL

- It is a broader definition for health-related quality of life, where:
- Pain, nausea and vomiting are understood/considered a trade-off for the technical success of ops
- Symptoms as consequences
- Most clinicians report they would not consider them.

### A REVELATION

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## THE SPHERE OF CARE

### What Is The Role Of Hospital Registries?



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### QoL Outcomes are Commonly & Broadly Used in Trials

**Common** - e.g. pain, nausea, QoL, etc.  
**Common** - e.g. adherence, compliance, toxicity, etc.  
**Common** - e.g. mortality, hospital stay, etc.



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# **Which of the following might be considered measurable for PROMs?**

post Tx sexual function

exercise frequency & duration

religious beliefs

depression